EQ-5D-5L User Guide

Basic information on how to use the EQ-5D-5L instrument

Version 1.0

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Prepared by:

Rosalind Rabin
Mandy Oemar
Mark Oppe
Bas Janssen
Michael Herdman

EuroQol Group Executive Office
On behalf of the EuroQol Group

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1. Introduction

This guide has been developed in order to give users basic information on how to use the EQ-5D-5L version. Topics include administering the instrument, setting up a database for data collected using EQ-5D-5L as well as information about how to present the results. Also included are several frequently asked questions dealing with common issues regarding the use of EQ-5D-5L and a list of currently available EuroQol Group products.

1.1. The EuroQol Group

- The EuroQol Group is a network of international multidisciplinary researchers devoted to the measurement of health status. Established in 1987, the EuroQol Group originally consisted of researchers from Europe, but nowadays includes members from North America, Asia, Africa, Australia, and New Zealand. The Group is responsible for the development of EQ-5D, a preference based measure of health status that is now widely used in clinical trials, observational studies and other health surveys.
- The EuroQol Group has been holding annual scientific meetings since its inception in 1987.
- The EuroQol Group can be justifiably proud of its collective scientific achievements over the last 20 years. Research areas include: valuation, EQ-5D use in clinical studies and in population surveys, experimentation with the EQ-5D descriptive system, computerized applications, interpretation of EQ-5D ratings and the role of EQ-5D in measuring social inequalities in self-reported health.
- The EuroQol Group's website (www.euroqol.org) contains detailed information about EQ-5D, guidance for users, a list of available language versions, EQ-5D references and contact details.

1.2. EQ-5D

EQ-5D is a standardised measure of health status developed by the EuroQol Group in order to provide a simple, generic measure of health for clinical and economic appraisal.[1] Applicable to a wide range of health conditions and treatments, it provides a simple descriptive profile and a single index value for health status that can be used in the clinical and economic evaluation of health care as well as in population health surveys.

EQ-5D is designed for self-completion by respondents and is ideally suited for use in postal surveys, in clinics, and in face-to-face interviews. It is cognitively undemanding, taking only a few minutes to complete. Instructions to respondents are included in the questionnaire.

1.2.1. EQ-5D-3L

The EQ-5D 3 level version (EQ-5D-3L) was introduced in 1990. The EQ-5D-3L essentially consists of 2 pages - the EQ-5D descriptive system (page 2) and the EQ visual analogue scale (EQ VAS) (page 3). The EQ-5D-3L descriptive system comprises the following 5 dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has 3 levels: no problems, some problems, extreme problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in

[1] EuroQol Group. EuroQol-a new facility for the measurement of health-related quality of life. Health Policy 1990;16:199-208

the box against the most appropriate statement in each of the 5 dimensions. The EQ VAS records the respondent's self-rated health on a vertical, visual analogue scale where the endpoints are labelled 'Best imaginable health state' and 'Worst imaginable health state'. This information can be used as a quantitative measure of health outcome as judged by the individual respondents.

The EQ-5D-3L has now been translated into more than 150 languages and is used worldwide. However ceiling effects have been reported, particularly when used in general population surveys but also in some patient population settings. In order to address these criticisms, and encouraged by demand from clinicians and other users, the EuroQol Group decided to explore ways of improving the EQ-5D's measurement properties.

1.2.2. EQ-5D-5L

In 2005, a Task Force was established within the EuroQol Group to investigate methods to improve the instrument's sensitivity and to reduce ceiling effects. After much discussion, the Task Force decided that there should be no change in the number of dimensions for a new version of EQ-5D. However, previously published studies by EuroQol Group members showed that experimental 5-level versions of EQ-5D could significantly increase reliability and sensitivity (discriminatory power) while maintaining feasibility and potentially reducing ceiling effects. The Group therefore decided that the new version of the EQ-5D should include five levels of severity in each of the existing five EQ-5D dimensions and that it would be called the EQ-5D-5L (Figure 1)[2]. The existing EQ-5D will be renamed the EQ-5D-3L.

The EQ-5D-5L still consists of 2 pages – the EQ-5D-5L descriptive system (page 2) and the EQ visual Analogue scale (EQ VAS) (page 3). The descriptive system comprises the same 5 dimensions as the EQ-5D-5D-3L (mobility, self care, usual activities, pain/discomfort, anxiety/depression). However, each dimension now has 5 levels: no problems, slight problems, moderate problems, severe problems, and extreme problems. The respondent is asked to indicate his/her health state by ticking (or placing a cross) in the box against the most appropriate statement in each of the 5 dimensions. This decision results in a 1-digit number expressing the level selected for that dimension. The digits for 5 dimensions can be combined in a 5-digit number describing the respondent's health state. **It should be noted that the numerals 1-5 have no arithmetic properties and should not be used as a cardinal score.** During the development of the EQ-5D-5L, the opportunity was also taken to improve some of the wording in the dimensions to enhance consistency and facilitate understanding. For example, the old wording of 'confined to bed' to indicate the upper extreme in the EQ-5D-3L has been replaced with 'I am unable to walk about' which is more consistent with the wording within the Mobility dimension and with the extreme levels on other dimensions.

The EQ VAS records the respondent's self-rated health on a 20 cm vertical, visual analogue scale with endpoints labelled 'the best health you can imagine' and 'the worst health you can imagine'. This information can be used as a quantitative measure of health as judged by the individual respondents. The instructions for the EQ VAS task have been changed and simplified in the EQ-5D-5L. The EuroQol Group had received feedback over the years that respondents sometimes found it difficult to draw a line from the box to the

[2] Herdman M, Gudex C, Lloyd A, Janssen MF, Kind P, Parkin D, Bonsel G, Badia X. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Quality of Life Research (accepted for publication).

scale. It was also cumbersome for administrators to record their scores. The EQ-5D-5L now asks respondents to simply ‘mark an X on the scale to indicate how your health is TODAY’ and then to ‘write the number you marked on the scale in the box below’. This should make the task easier for both respondents and users.

Figure 1: EQ-5D-5L (UK English sample version)

Under each heading, please tick the **ONE** box that best describes your health **TODAY**

MOBILITY

I have no problems in walking about ❑
I have slight problems in walking about ❑
I have moderate problems in walking about ❑
I have severe problems in walking about ❑
I am unable to walk about ❑

SELF-CARE

I have no problems washing or dressing myself ❑
I have slight problems washing or dressing myself ❑
I have moderate problems washing or dressing myself ❑
I have severe problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ❑
I have slight problems doing my usual activities ❑
I have moderate problems doing my usual activities ❑
I have severe problems doing my usual activities ❑
I am unable to do my usual activities ❑

PAIN / DISCOMFORT

I have no pain or discomfort ❑
I have slight pain or discomfort ❑
I have moderate pain or discomfort ❑
I have severe pain or discomfort ❑
I have extreme pain or discomfort ❑

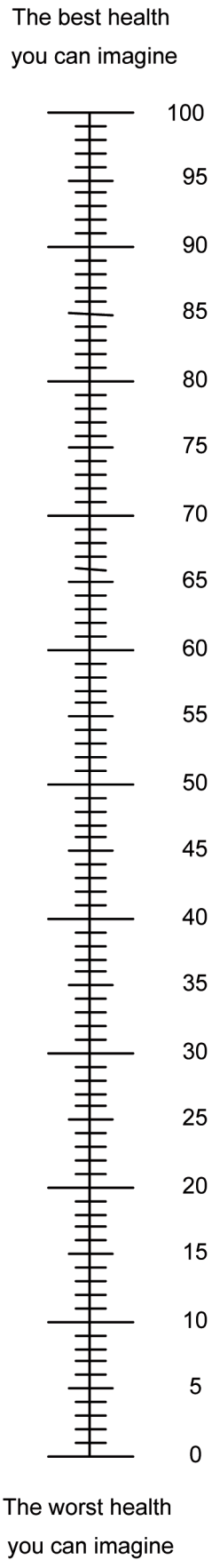
ANXIETY / DEPRESSION

I am not anxious or depressed ❑
I am slightly anxious or depressed ❑
I am moderately anxious or depressed ❑
I am severely anxious or depressed ❑
I am extremely anxious or depressed ❑

SAMPLE

- We would like to know how good or bad your health is **TODAY**.
- This scale is numbered from **0** to **100**.
- **100** means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an **X** on the scale to indicate how your health is **TODAY**.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY= ☐



SAMPLE

1.3. What is a health state?

Each of the 5 dimensions comprising the EQ-5D descriptive system is divided into 5 levels of perceived problems:

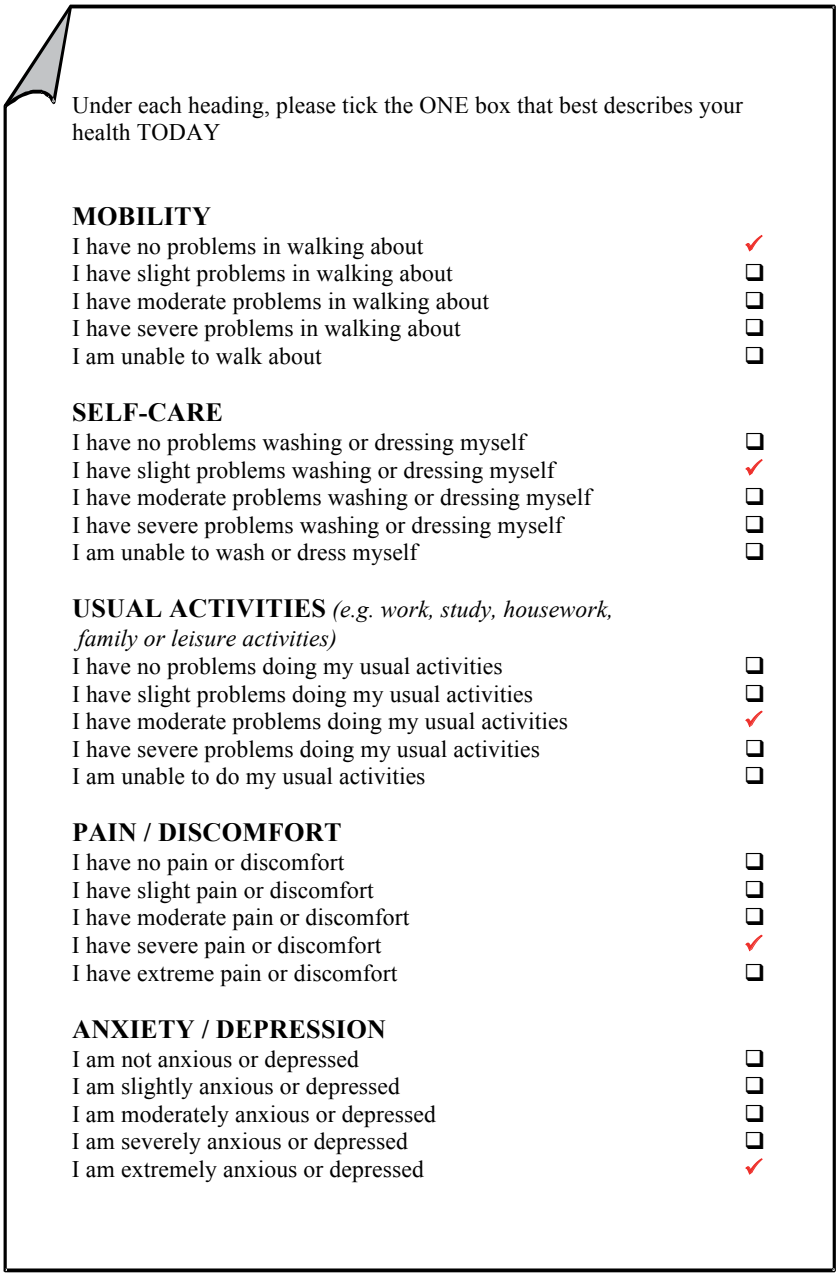
Level 1: indicating no problem
Level 2: indicating slight problems
Level 3: indicating moderate problems
Level 4: indicating severe problems
Level 5: indicating extreme problems

A unique health state is defined by combining 1 level from each of the 5 dimensions.

A total of 3125 possible health states is defined in this way. Each state is referred to in terms of a 5 digit code. For example, state 11111 indicates no problems on any of the 5 dimensions, while state 12345 indicates no problems with mobility, slight problems with washing or dressing, moderate problems with doing usual activities, severe pain or discomfort and extreme anxiety or depression.

2. Scoring the EQ-5D-5L descriptive system

The EQ-5D-5L descriptive system should be scored, for example, as follows:



Under each heading, please tick the ONE box that best describes your health TODAY

MOBILITY
- I have no problems in walking about ✓
- I have slight problems in walking about ☐
- I have moderate problems in walking about ☐
- I have severe problems in walking about ☐
- I am unable to walk about ☐

SELF-CARE
- I have no problems washing or dressing myself ☐
- I have slight problems washing or dressing myself ✓
- I have moderate problems washing or dressing myself ☐
- I have severe problems washing or dressing myself ☐
- I am unable to wash or dress myself ☐

USUAL ACTIVITIES *(e.g. work, study, housework, family or leisure activities)*
- I have no problems doing my usual activities ☐
- I have slight problems doing my usual activities ☐
- I have moderate problems doing my usual activities ✓
- I have severe problems doing my usual activities ☐
- I am unable to do my usual activities ☐

PAIN / DISCOMFORT
- I have no pain or discomfort ☐
- I have slight pain or discomfort ☐
- I have moderate pain or discomfort ☐
- I have severe pain or discomfort ✓
- I have extreme pain or discomfort ☐

ANXIETY / DEPRESSION
- I am not anxious or depressed ☐
- I am slightly anxious or depressed ☐
- I am moderately anxious or depressed ☐
- I am severely anxious or depressed ☐
- I am extremely anxious or depressed ✓

Levels of perceived problems are coded as follows:

✓	
☐	
☐	
☐	Level 1 is coded as a '1'
☐	
☐	
✓	Level 2 is coded as a '2'
☐	
☐	
☐	
☐	
☐	Level 3 is coded as a '3'
✓	
☐	
☐	
☐	Level 4 is coded as a '4'
☐	
✓	
☐	
☐	
☐	Level 5 is coded as a '5'
☐	
☐	
✓	

This example identifies the health state '12345'.

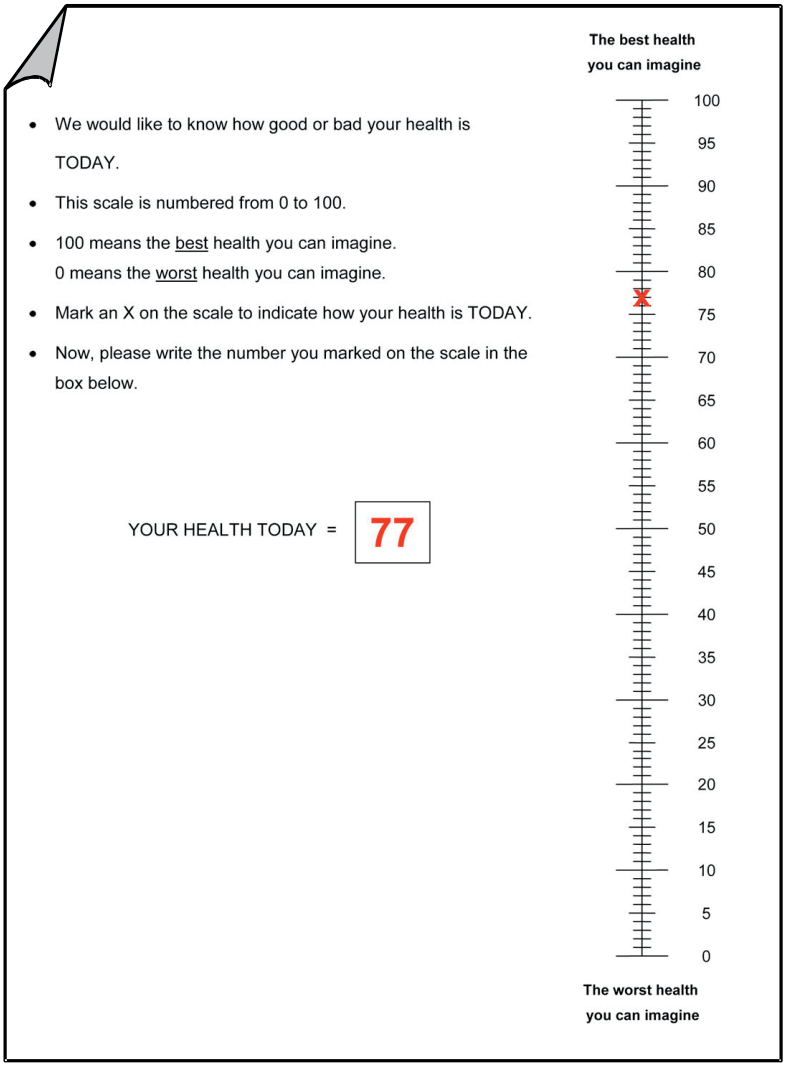
NB: *There should be only <u>ONE</u> response for each dimension*

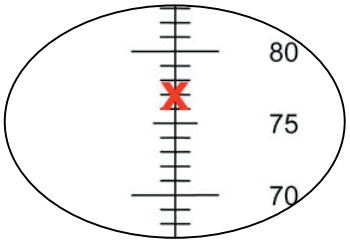
NB: Missing values *can be coded as '9'.*

NB: Ambiguous values *(e.g. 2 boxes are ticked for a single dimension) should be treated as missing values.*

3. Scoring the EQ VAS

The EQ VAS should be scored, for example, as follows:





For example this response should be coded as 77

NB: Missing values *should be coded as '999'.*

NB: *If there is a discrepancy between where the respondent has placed the X and the number he/she has written in the box, administrators should use the number in the box.*

4. Converting EQ-5D-5L states to an index value

EQ-5D-5L health states, defined by the EQ-5D-5L descriptive system, may be converted into a single index value[3]. The index values, presented in country specific value sets, are a major feature of the EQ-5D instrument, facilitating the calculation of quality-adjusted life years (QALYs) that are used to inform economic evaluations of health care interventions. Pilot studies that directly elicit preferences from general populations in order to derive index-based values for the EQ-5D-5L are currently underway in a number of countries (Argentina, Canada, China, England, the Netherlands, Singapore, Spain, US). However, it will take 2 – 3 years to complete and publish definitive valuation studies and for results to be available to EQ-5D-5L users. Until then, a "crosswalk" between the EQ-5D-3L index values and the new EQ-5D-5L descriptive system has been undertaken, resulting in "crosswalk" value sets for the new EQ-5D-5L descriptive system.

The EQ-5D-5L Crosswalk Project, coordinated by the EuroQol Group, was conducted on 3691 patients across six countries. The crosswalk establishes a link or "bridge" between the EQ-5D-3L and EQ-5D-5L descriptive systems. This link is based on responses of patients who completed both the EQ-5D-3L and EQ-5D-5L instruments. Several methods were consequently tested to optimize the link function between the two descriptive systems. The crosswalk link function resulting from this exercise can be used to calculate index values for EQ-5D-5L, based on the existing value sets for the EQ-5D-3L. Value sets have been derived for EQ-5D-3L in several countries using the EQ-5D visual analogue scale (EQ-5D VAS) valuation technique or the time trade-off (TTO) valuation technique. The list of currently available value sets with the number of respondents and valuation technique applied is presented in table 1. Most of the EQ-5D-3L value sets have been obtained using a representative sample of the general population, thereby ensuring that they represent the societal perspective. For anyone working with EQ-5D-3L data, an essential guide to the Group's available value sets can be found in: EuroQol Group Monograph series: Volume 2: EQ-5D value sets: inventory, comparative review and user guide, recently published by Springer (see section 8 for more information).

EQ-5D-5L value sets are available for each country that performed a valuation study for the EQ-5D-3L (table 1). By using the crosswalk link function and the individual responses to the EQ-5D-5L descriptive system, index values for the EQ-5D-5L can be calculated.

[3] Many different terms are in use for these index values, such as preference weights, preference-based values, utilities, QALY weights, etc. Here, we use the term 'index value'.

Table 1: List of available value sets (references available on the website)

Country	N	Valuation method
Belgium	722	EQ-5D VAS
Denmark	1686	EQ-5D VAS
Denmark	1332	TTO
Europe	8709	EQ-5D VAS
Finland	1634	EQ-5D VAS
France	443	VAS/TTO
Germany	339	EQ-5D VAS
Germany	339	TTO
Japan	621	TTO
Netherlands	309	TTO
New Zealand	1360	EQ-5D VAS
Slovenia	733	EQ-5D VAS
Spain	300	EQ-5D VAS
Spain	1000	TTO
Thailand	1324	TTO
UK	3395	EQ-5D VAS
UK	3395	TTO
US	4048	TTO
Zimbabwe	2440	TTO

In development:

Canada, Chile, Italy and Singapore

Documents containing information on the crosswalk project, tables of values for all 3125 health states, and syntax files for calculating the crosswalk index values can be ordered from the EuroQol Executive Office.

5. Organising EQ-5D-5L data

Data collected using EQ-5D-5L can be entered in a database according to the following schema:

Variable name	ID	SEX	AGE	EDU	COUNTRY	YEAR	MOBILITY
Variable description	patient ID number	1=Male 2=Female 9=Missing value	999=Missing value	1=Low 2=Medium 3=High 9=Missing value	Country where data was collected	Year in which data was collected	1=No problems, 2=Slight problems 3=Moderate problems 4=Severe problems 5=Unable to 9=Missing value
Data row 1	1001	1	43	1	UK	2011	4
Data row 2	1002	2	24	2	UK	2011	2

Variable name	SELFCARE	ACTIVITY	PAIN	ANXIETY	STATE	EQ_VAS
Variable description	1=No problems 2=Slight problems 3=Moderate problems 4=Severe problems 5=Unable to 9=Missing value	1=No problems 2=Slight problems 3=Moderate problems 4=Severe problems 5=Unable to 9=Missing value	1=No pain 2=Slight pain 3=Moderate pain 4=Severe pain 5=Extreme pain 9=Missing value	1=Not anxious 2=Slightly anxious 3=Moderately anxious 4=Severely anxious 5=Extremely anxious 9=Missing value	5 digit code for EQ-5D-5L	999=Missing value
Data row 1	1	3	2	5	41325	60
Data row 2	1	1	1	1	21111	90

6. Presenting EQ-5D-5L results

Data collected using EQ-5D-5L can be presented in various ways. A basic subdivision can be made according to the structure of the EQ-5D-5L:

1. Presenting results from the EQ-5D-5L descriptive system as a health profile
2. Presenting results of the EQ VAS as a measure of overall self-rated health status
3. Presenting results from the EQ-5D-5L index value

The way results can be presented is determined both by the data and by what message you, as a researcher, wish to convey to your audience.

6.1. Health profiles

One way of presenting data as a health profile is by making a table with the frequency or the proportion of reported problems for each level for each dimension. These tables can be broken down to include the proportions per subgroup, such as age, before vs. after treatment, treatment vs. comparator, etc.

Sometimes it is more convenient to dichotomise the EQ-5D-5L levels into 'no problems' (i.e. level 1) and 'problems' (i.e. levels 2 to 5), therefore changing the profile into frequencies of reported problems. This can be the case, for example, in a general population survey where the numbers of reported problems are low. Tables 2 and 3 are examples of how to present EQ-5D-5L data in tabulated form.

Table 2: Percentage of a general population sample reporting levels 1 to 5 by dimension and by age group

		AGE GROUPS						
EQ-5D DIMENSION		***18-29***	***30-39***	***40-49***	***50-59***	***60-69***	***70+***	***TOTAL***
MOBILITY	Level 1	95,2%	90,7%	87,2%	67,8%	78,9%	47,1%	**86,0%**
	Level 2	4,4%	8,1%	10,1%	18,6%	14,1%	41,2%	**10,2%**
	Level 3	0,4%	0,6%	2,1%	10,2%	4,2%	5,9%	**2,7%**
	Level 4	0,0%	0,6%	0,5%	3,4%	2,8%	5,9%	**1,1%**
	Level 5	0,0%	0,0%	0,0%	0,0%	0,0%	0,0%	**0,0%**
SELF-CARE	Level 1	98,0%	96,9%	97,3%	91,5%	91,5%	88,2%	**95,9%**
	Level 2	0,4%	1,9%	2,7%	6,8%	8,5%	5,9%	**3,0%**
	Level 3	0,8%	1,2%	0,0%	0,8%	0,0%	5,9%	**0,7%**
	Level 4	0,4%	0,0%	0,0%	0,0%	0,0%	0,0%	**0,1%**
	Level 5	0,4%	0,0%	0,0%	0,8%	0,0%	0,0%	**0,2%**
USUAL ACTIVITY	Level 1	66,5%	64,6%	54,3%	37,3%	50,7%	41,2%	**57,1%**
	Level 2	30,7%	29,8%	36,7%	41,5%	39,4%	41,2%	**34,5%**
	Level 3	1,6%	5,0%	8,5%	14,4%	7,0%	17,6%	**6,6%**
	Level 4	0,8%	0,6%	0,5%	6,8%	2,8%	0,0%	**1,7%**
	Level 5	0,4%	0,0%	0,0%	0,0%	0,0%	0,0%	**0,1%**

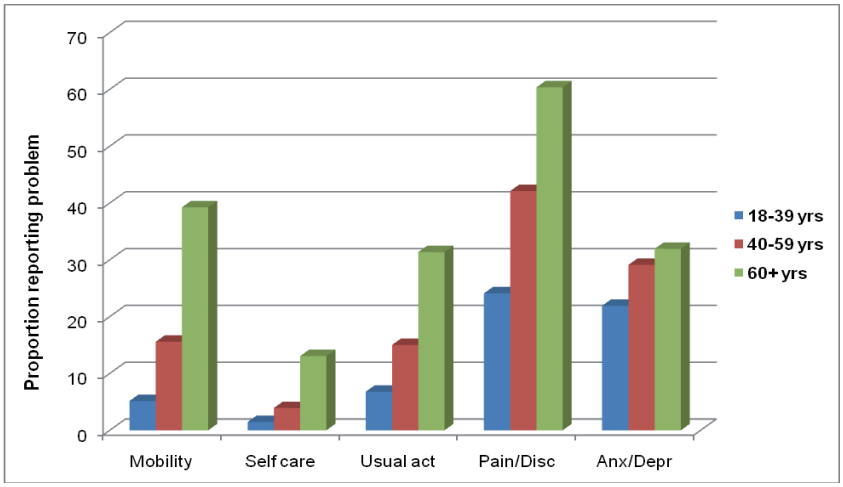
EQ-5D DIMENSION		AGE GROUPS 18-29	30-39	40-49	50-59	60-69	70+	TOTAL
PAIN / DISCOMFORT	Level 1	79,3%	75,2%	75,0%	78,0%	78,9%	94,1%	**77,5%**
	Level 2	16,3%	19,3%	19,7%	17,8%	15,5%	0,0%	**17,5%**
	Level 3	2,8%	4,3%	4,3%	2,5%	5,6%	5,9%	**3,7%**
	Level 4	1,2%	1,2%	1,1%	1,7%	0,0%	0,0%	**1,1%**
	Level 5	0,4%	0,0%	0,0%	0,0%	0,0%	0,0%	**0,1%**
ANXIETY / DEPRESSION	Level 1	92,4%	85,1%	83,5%	65,3%	84,5%	82,4%	**84,0%**
	Level 2	6,8%	9,3%	11,7%	19,5%	9,9%	11,8%	**10,7%**
	Level 3	0,0%	4,3%	3,2%	11,9%	4,2%	5,9%	**3,8%**
	Level 4	0,4%	1,2%	1,6%	3,4%	1,4%	0,0%	**1,4%**
	Level 5	0,4%	0,0%	0,0%	0,0%	0,0%	0,0%	**0,1%**

Table 3: Frequency of reported problems for a general population sample by dimension and age group

EQ-5D DIMENSION		AGE GROUPS 18-29	30-39	40-49	50-59	60-69	70-79	TOTAL
MOBILITY	No problems	239	146	164	80	56	8	**693**
	Problems	12	15	24	38	15	9	**113**
SELF-CARE	No problems	246	156	183	108	65	15	**773**
	Problems	5	5	5	10	6	2	**33**
USUAL ACTIVITY	No problems	167	104	102	44	36	7	**460**
	Problems	84	57	86	74	35	10	**346**
PAIN / DISCOMFORT	No problems	199	121	141	92	56	16	**625**
	Problems	52	40	47	26	15	1	**181**
ANXIETY / DEPRESSION	No problems	232	137	157	77	60	14	**677**
	Problems	19	24	31	41	11	3	**129**

In addition to presenting the results in tabulated form, you can also use graphical presentations. Two (or three) dimensional bar charts can be used to summarise the results in a single graph (see Figure 2). Figure 2 shows the sum of the proportion of reported levels 2 to 5 for each of the 5 EQ-5D-5L dimensions for 3 different age groups. Older people reported more problems on all dimensions but the effect of age was strongest for mobility and weakest for anxiety/depression.

Figure 2: Profile of the population (% reporting problem



6.2. EQ VAS

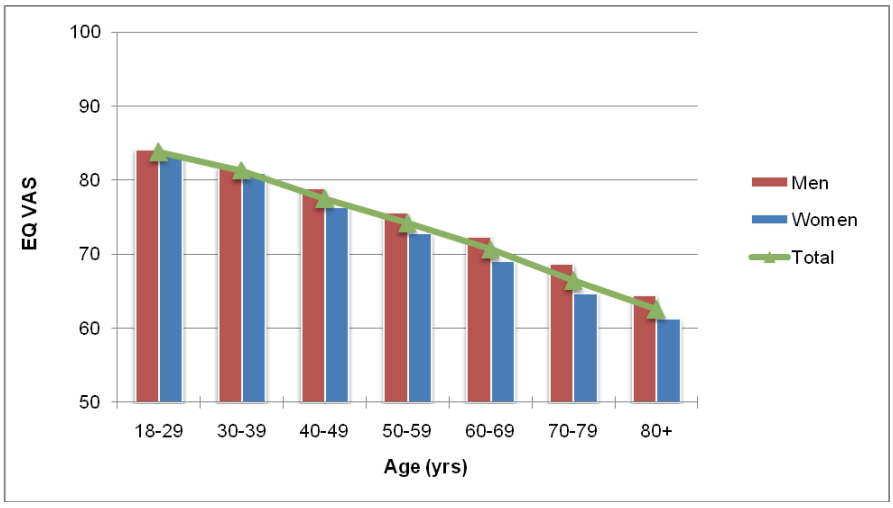
In order to present all aspects of the EQ VAS data, you should present both a measure of the central tendency and a measure of dispersion. This could be the mean values and the standard deviations or, if the data are skewed, the median values and the 25th and 75th percentiles. An example is presented in table 4.

Table 4: EQ VAS values by age – mean + standard deviation and median + percentiles

EQ VAS	AGE GROUPS						
	18-29	*30-39*	*40-49*	*50-59*	*60-69*	*70+*	*TOTAL*
Mean	85,7	84,3	83,7	79,7	86,1	79,0	**84,0**
- Std Dev	10,1	12,6	13,3	14,0	11,1	22,6	**12,6**
Median	88,0	89,0	88,0	80,5	90,0	80,0	**86,0**
- 25th	80,0	80,0	75,0	73,3	79,0	73,5	**80,0**
- 75th	93,0	91,0	93,8	90,0	95,0	92,0	**92,0**

You can present a graphical representation of the data by using bar charts, line charts, or both (see figure 3). Figure 3 shows the mean EQ VAS scores reported by men, women and both for 7 different age groups. Mean EQ VAS scores are seen to decrease with increasing age. Also, men in all age groups reported higher EQ VAS scores than women.

Figure 3: Mean population EQ VAS scores by age group and sex



6.3. EQ-5D-5L index value

EQ-5D-5L index values can be presented in much the same way as EQ VAS data, i.e. using both a measure of central tendency and a measure of dispersion. These can be mean values and standard deviations (or standard errors, or 95% confidence intervals) or again, if the data are skewed, median values and the 25th and 75th percentiles. Tables 5 and 6 and figures 4 and 5 show 2 examples of how to present EQ-5D-5L index value results. Table 5 and figure 4 present the results from a study in which the effect of a treatment on health status is investigated. Table 6 and figure 5 show results for a patient population and 3 subgroups.

Table 5: EQ-5D-5L index values before and after treatment

EQ-Index	Before treatment	After treatment
Mean	0,59	0,76
- Std error	0,012	0,015
Median	0,60	0,70
- 25th	0,50	0,65
- 75th	0,70	0,80
N	120	110

Table 6: EQ-5D-5L index values for the total patient population and the 3 subgroups

EQ-Index	All patients	Subgroup 1	Subgroup 2	Subgroup 3
Mean	0,66	0,45	0,55	0,90
- Std error	0,010	0,013	0,015	0,010
Median	0,55	0,40	0,55	0,95
- 25th	0,50	0,30	0,50	0,80
- 75th	0,70	0,50	0,60	1,00
N	300	100	75	125

Figure 4: EQ-5D-5L index values before and after treatment: mean values and 95% confidence intervals

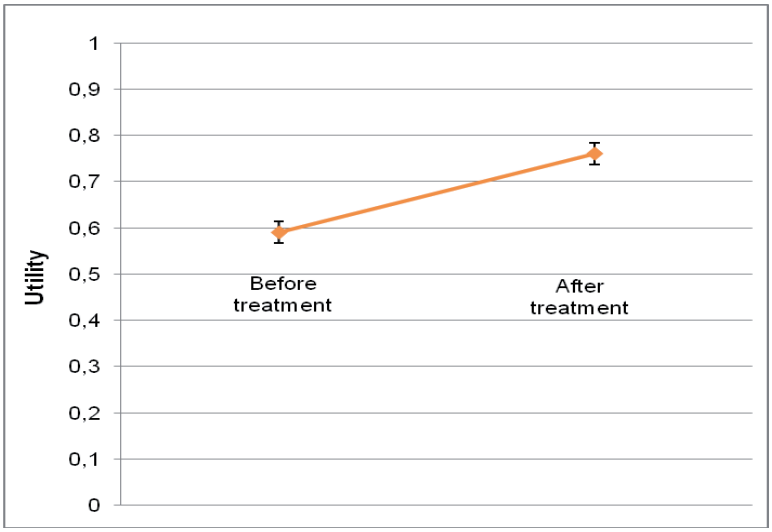
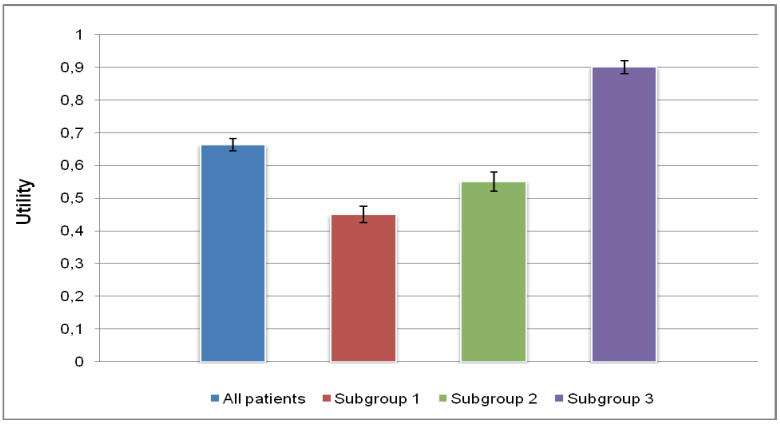


Figure 5: Mean EQ-5D-5L index values and 95% confidence intervals for the total patient population and 3 subgroups.



7. EQ-5D Products

7.1. EQ-5D-5L Translations and other formats

The **EQ-5D-5L** self-complete paper version is currently available in **more than 50** different language versions. If you want to know whether an EQ-5D-5L version exists for your country, please consult the website (www.euroqol.org).

Likewise, although the EQ-5D-5L was primarily designed as a pen-and-paper, self-complete instrument, it will increasingly become available in alternative formats and modes of administration. These include:

- Tablet and web-based versions
- PDA versions
- IVR
- Proxy versions
- Versions for telephone and face-to-face interviews

If you are interested in using one of these alternative formats or modes of administration, please contact the EuroQol Executive Office

7.2. Other EQ-5D Products

7.2.1. EQ-5D-3L Translations and formats

The EQ-5D-3L (EQ-5D 3 level) self complete paper version is currently translated in **more than 150** language versions. If you want to know whether an EQ-5D-3L language version exists for your country, please consult the website (www.euroqol.org).

Likewise, although the EQ-5D-3L was also primarily designed as a pen-and-paper self-complete instrument, it is now available in alternative formats and modes of administration, and in multiple translations e.g.

- Tablet and web-based versions
- PDA versions
- IVR
- Proxy versions
- Versions for telephone and face-to-face interviews

7.2.2. EQ-5D-Y Translations

The **EQ-5D-Y** is an EQ-5D-3L self complete youth version for children and adolescents aged 7-12 years. At present, this version is available in **9** different languages. If you want to know if there is an EQ-5D-Y version appropriate for your country, please consult the website (www.euroqol.org).

7.3. Translation process

All translation/adaptations of EQ-5D are produced using a standardized translation protocol that conforms to internationally recognized guidelines. These guidelines aim to ensure equivalence to the English 'source' version and involve a forward/backward translation process and cognitive debriefing. Only the EuroQol Executive Office can give permission for a translation to be performed and translations can only be stamped as official if they are performed in cooperation with EuroQol Group reviewers.

7.4. How to obtain EQ-5D

All self-report versions and alternative modes of administration and different languages must be obtained exclusively from the EuroQol Executive Office. IVR, web, tablet and PDA versions are exclusively provided via the EuroQol Group's preferred vendors. Normally only the language(s) appropriate to the country where the research request originates will be supplied. Licensing fees are determined by the EuroQol Executive Office on the basis of information provided by the user. Whether a fee is appropriate depends upon the type of study, size and/or number of patients/respondents and requested languages.

8. FAQ's

1. **For what period of time does EQ-5D-5L record health status?**

   Self-reported health status captured by EQ-5D-5L relates to the respondent's situation at the time of completion. No attempt is made to summarise recalled health status over the preceding days or weeks, although EQ-5D-3L has been tested in recall mode. An early decision taken by the EuroQol Group determined that health status measurement ought to apply to the respondent's immediate situation - hence the focus on 'your health **today**'.

2. **Can I use only the EQ-5D-5L descriptive system or only the EQ VAS?**

   We cannot advise this. EQ-5D-5L is a 2-part instrument so if you only use one part you cannot claim to have used EQ-5D-5L in your publications.

3. **How long should the EQ VAS be?**

   Officially, for paper versions, the EQ VAS scale should be 20 cm. All methodological and developmental work has been carried out using this length. To ensure that you print the correct length, make sure your paper size is set at A4 and the box in your printing instructions labelled 'scale to paper size' is set at 'no scaling'.

4. **Can I publish our study using EQ-5D?**

   Yes, you are free to publish your results. If you are reproducing the EQ-5D-5L in an appendix we request that you use the sample version of EQ-5D-5L and that the following text plus the date the version was translated is included in the footer: © *1990 EuroQol Group. EQ-5D™ is a trade mark of the EuroQol Group.*

5. **What is the difference between the EQ-5D-5L descriptive system and the EQ VAS?**

   The descriptive system can be represented as a health state, e.g. health state 21143 represents a patient who indicates slight problems on the mobility dimension, no problems on the self-care and usual activities dimensions, severe pain or discomfort, and moderate problems on the anxiety/depression dimension. These health states can be converted to a single index value using the crosswalk link function based on the existing value sets for the EQ-5D-3L described in Section 4 above. These EQ-5D-3L value sets are based on VAS or TTO valuation techniques, and reflect the opinion of the general population. The EQ VAS scores are patient-based and are therefore not representative of the general population. The EQ VAS self-rating records the respondent's own assessment of their health status. The EQ VAS scores however are anchored on 100 = the best health you can imagine and 0 = the worst health you can imagine, whereas the value sets are anchored on 11111 = 1 and dead = 0 and can therefore be used in QALY calculations.

6. What is the difference between the VAS and TTO techniques?

The difference between the TTO- and VAS-based value sets is that the techniques used to elicit the values on which the models are based differ. In the TTO task, respondents are asked to imagine that they will live in a certain health state (e.g. 33333) for 10 years and have to specify the amount of time they would be willing to give up to live in full health instead (i.e. 11111). For example, someone might find 8 years in 11111 equivalent to 10 years in 33333. The VAS technique on the other hand, asks people to indicate where, on a vertical thermometer-like scale ranging from best imaginable health to worst imaginable health, they think a health state should be positioned.

7. General population value sets vs. patient population value sets

If you want to undertake a utility analysis you will need to use a value set. Generally speaking, utility analysis requires a general population-based value set (as opposed to a patient-based set). The rationale behind this is that the values should reflect the preferences of local taxpayers and potential receivers of healthcare. Additionally, patients tend to rate their health states higher than the general population because of coping or other factors, and may therefore underestimate their need for healthcare. EQ-5D-5L value sets are therefore based on general population values.

8. Multinational clinical trials

Information relating to EQ-5D-5L health states gathered in the context of multinational trials may be converted into a single index value using the crosswalk link function based on the available EQ-5D-3L value sets as described in Section 4 above. There are different options available to do this using appropriate value sets- however the choice depends on the context in which the information will be used by researchers or decision makers. In cases where data from an international trial are to be used to inform decision makers in a specific country, it seems reasonable to expect decision makers to be interested primarily in value sets that reflect the values for health states in that country. So for example, if applications for reimbursement of a drug are rolled out from country to country, country-specific value sets should be applied and reported in each pharmaco-economic report. This is no different from the requirement to use country specific costs. In the absence of a country-specific value set, the researcher should select another set of values for a population that most closely approximates that country. Sometimes however, information about index values ('utilities') is required to inform researchers or decision makers in an international context. In these instances, one value set applied over all health states data is probably more appropriate. The decision about which value set to use will also depend on whether the relevant decision making body in each country specifies any requirements or preferences in regard to the methodology used in different contexts (e.g. TTO, standard gamble (SG), VAS or discrete choice modelling (DCM)). These guidelines are the topic of an on-going, international debate but the

EuroQol Group website is planning to provide a summary of health care decision-making bodies internationally together with their stated requirements regarding the valuation of health states. Detailed information on valuation protocols together with guidelines on which value set to use and tables of all available value sets has recently been published by Springer in: EuroQol Group Monograph series: Volume 2: EQ-5D value sets: inventory, comparative review and user guide' (see section 8 for more information). Chapter 4 by Nancy Devlin and David Parkin will be of special interest to researchers pondering the issue of which value set to use.

9. Additional information

9.1. Key EuroQol Group references

1. The EuroQol Group (1990). EuroQol-a new facility for the measurement of health-related quality of life. Health Policy 16(3):199-208.

2. Brooks R (1996). EuroQol: the current state of play. Health Policy 37(1):53-72.

3. Dolan P (1997). Modeling valuations for EuroQol health states. Med Care 35(11):1095-108.

4. Roset M, Badia X, Mayo NE (1999). Sample size calculations in studies using the EuroQol 5D. Qual Life Res 8(6):539-49.

5. Greiner W, Weijnen T, Nieuwenhuizen M, et al. (2003). A single European currency for EQ-5D health states. Results from a six country study. Eur J Health Econ; 4(3):222-231.

6. Shaw JW, Johnson JA, Coons SJ (2005). US valuation of the EQ-5D health states: development and testing of the D1 valuation model. Med Care; 43(3): 203-220.

7. Herdman M, Gudex C, Lloyd A, Janssen MF, Kind P, Parkin D, Bonsel G, Badia X. Development and preliminary testing of the new five-level version of EQ-5D (EQ-5D-5L). Quality of Life Research (accepted for publication).

9.2. Referring to the EQ-5D instrument in publications

When publishing results obtained with the EQ-5D, the following references can be used:

1. The EuroQol Group (1990). EuroQol-a new facility for the measurement of health-related quality of life. Health Policy 16(3):199-208.

2. Brooks R (1996). EuroQol: the current state of play. Health Policy 37(1):53-72.

If you used a value set in your study you can also include a reference to the publication regarding that value set. The appropriate references for the value sets can be found in the EQ-5D Value Sets Monograph and in the value set summary documents that can be ordered from the EuroQol Executive Office.

9.3. EQ-5D Books

The Measurement and valuation of health status using EQ-5D: A European perspective. Eds Brooks R, Rabin R, de Charro F. Kluwer Acacemic Publishers, 2005

This book reports on the results of the European Union-funded EQ-net project which furthered the development of EQ-5D in the key areas of valuation, application and translation. The book can be obtained from Springer at www.springeronline.com at a cost of € 107.95.

EQ-5D concepts and methods: a developmental history. Eds Kind P, Brooks R, Rabin R. Springer, 2005.

This book is a collection of papers representing the collective intellectual enterprise of the EuroQol Group and can be obtained from Springer at www.springeronline.com at a cost of € 85.00.

EQ-5D value sets: Inventory, comparative review and user guide. Eds. Szende A, Oppe M, Devlin N. EuroQol Group Monographs Volume 2. Springer, 2006.

This book provides an essential guide to the use of the EuroQol Group's value sets for anyone working with EQ-5D data and can be obtained from Springer at www.springeronline.com at a cost of € 49.95.

EuroQol Group
Marten Meesweg 107
3068 AV Rotterdam
The Netherlands

+31 (0)88 4400190
userinformationservice@euroqol.org

www.euroqol.org